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The mediating effect of sense of coherence on the caregiver ability–caregiver burden relationship for caregivers of children with liver transplantation in China

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ABSTRACT

Background: Caregivers of children who have had liver transplantation often experience chronic care stress. Previous studies have focused on caregivers' negative feelings (e.g., caregiver burden), but few studies have focused on caregivers' positive feelings (e.g., sense of coherence) and caregiver ability.

Objectives: The study purpose was to investigate the status of the burden of caregivers of children with liver transplantation, and to explore the mediating role of sense of coherence between caregiver ability and caregiver burden.

Methods: There were 461 questionnaires collected from a tertiary-level hospital from caregivers of children who had liver transplantation from April to June 2022. Demographic data, Family Caregiver Task Inventory, Sense of Coherence Scale-13, and Zarit Burden Interview were used. The STROBE checklist was monitored.

Results: The average caregiver burden score was 32.19 ± 16.71. The distribution of caregiver burden levels was mild (42.52%), none (26.25%), moderate (24.95%), and severe (6.29%). Caregiver ability score was negatively correlated with caregiver burden score; however, sense of coherence score was negatively correlated with caregiver burden score. Caregiver ability partially mediated caregiver burden through sense of coherence (38.51%).

Conclusion: The caregiver burden level was not heavy in general. Both positive and negative feelings were present in caregivers. Caregiver ability also reduced the caregiver burden through sense of coherence.

Introduction

Congenital biliary atresia and hereditary metabolic diseases in children are often involved in liver lesions, which can lead to liver failure in the final stage (Akbulut et al., 2020). Liver transplantation is the only effective treatment method (Grimaldi et al., 2021). With the continuous development of liver transplantation surgery, increasing numbers of children with end-stage liver disease have another chance at life (Curnock et al., 2020). By 2020, China had become the country with the largest annual number of paediatric liver transplantation cases in the world (Xia & Zhu, 2022). Following liver transplantation, children showed a significantly improved survival rate, and the 5-year survival rate can exceed 90% (Liu et al., 2022). However, for the paediatric liver transplant community, success of the operation does not mean the cure of the disease, and the quality of postoperative management and care can determine the prognosis of the child (Xia & Zhu, 2022).

Paediatric liver transplant caregivers are under pressure from many sources (Ozdemi & Budak, 2022; Wei et al., 2018). Caregivers refer to family members or close relatives who are mainly responsible for providing unpaid care to patients (Wittenberg et al., 2021). On the one hand, due to the young age and limited cognitive and self-care abilities of children, caregivers need to assume many responsibilities, including physical care, symptom management, medicine dispensing, regular re-examination, nutrition management, psychological support, and clinical decision-making (Lerret et al., 2017). On the other hand, a caregiver needs to adapt to the child's constantly changing care needs at different

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stages as the child's age increases (e.g., children's education and work) (Ohnemus et al., 2020). In addition, there are the huge, long-term costs of health care (Dong et al., 2022). If things do not go as expected after surgery, the primary caregiver is an easy target for blame because she or he is both the decision maker and the caregiver (Wei et al., 2018). These pressures easily lead to caregiver burden. In addition to their responsibility of caring, primary caregivers are also often the first choice for liver donors (Yi et al., 2020; Zengin et al., 2021). When the primary caregiver is the liver donor, the dual roles of caregiver and patient need to be taken into account. Therefore, caregivers for paediatric liver transplantation bear a much higher burden than caregivers for other diseases (Miyazaki et al., 2010).

The caregiver burden comprises the negative physical, psychological, social, and economic impact on caregivers when caring for patients (Yi et al., 2020). Physically, the task of long-term load-bearing care takes a lot of time and energy, causing many health problems for the caregiver, such as weight loss, fatigue, sleep, and cognitive dysfunction (Dong et al., 2022; Miyazaki et al., 2010; Zhang et al., 2014). Psychologically, anxiety about illness and uncertainty about the child's future increase the risk of anxiety and depression for caregivers (Goetzinger et al., 2012). Studies have shown that caregivers from the first stage of liver transplantation had anxiety levels higher than the patients (Malik et al., 2014; Li, 2019). In terms of family and social functioning, the caregiver's family lifestyle and life role will change, and long-term care tasks will interfere with the caregiver's professional activities, leading to the interruption of a normal social life (Miyazaki et al., 2010; Wei et al., 2018; Yadav et al., 2017). Some studies have shown that caregivers, known as "invisible patients," have higher mortality rates and poorer quality of life (Kikuchi & Kamibeppu, 2015; Wei et al., 2018; Yang et al., 2012). The high care burden not only harms the caregiver in all aspects but also reduces their ability to provide continuous care for the patient, worsens the patient's prognosis, and affects the patient's recovery process and quality of life (Zhu et al., 2022).

However, the caregiver's response to stress is not always a negative adaptation, and caregivers can also experience positive feelings from caring activities (Chen et al., 2022; Dong et al., 2022). A recent study shows that in addition to the negative feelings of obvious physical and mental distress and multiple role adaptation conflicts, caregivers for paediatric liver transplantation also have positive psychology of contentment and positive attitude, gratitude, and social feedback (Dong et al., 2022). Positive psychology, such as sense of coherence (SOC), can help to identify caregivers experiencing a heavy burden and to a large extent allow effective interventions (Potier et al., 2018). The SOC refers to an individual's ability to utilise internal and external resources and perceive the meaning of life when facing stressors in life (Antonovsky, 1993). It also reflects an individual's universal, enduring, and dynamic sense of confidence when dealing with pressure. The SOC is a synthesis of comprehensibility, manageability, and meaningfulness (Antonovsky, 1993). A strong SOC involves the following aspects: (1) individuals perceive internal and external stressors as understandable; (2) the pressure is considered controllable due to sufficient internal and external resources; and (3) despite the challenges of diagnosis and recovery, life is still considered meaningful. Research has confirmed that high SOC is a protective factor for caregiver burden (Del-Pino-Casado et al., 2019).

Differing from patients with other diseases, the complexity and particularity of paediatric liver transplantation, the growth and development of children, and their physiological and psychological characteristics place higher requirements on caregivers' ability. Caregiver ability includes not only the knowledge and skills of caring for children but also the ability to adjust their physical and mental health and obtain social support (Farran Carol et al., 2009). Studies have shown that paediatric liver transplant caregivers have insufficient care readiness and ability to obtain nursing information and resources and deal with emergencies (Wadhwanii et al., 2022; Wang et al., 2022). This lack of caregiver ability easy places burdens on caregivers (Gao, 2021). Many studies have confirmed that the poorer the caregiver's ability is, the heavier is the caregiver's burden. Improving caregiver capacity can improve the quality of life (Fang et al., 2022; Schandl et al., 2022).

Caregiver ability and SOC play a role in moderating/buffering caregiver burden (Del-Pino-Casado et al., 2019; Ruisoto et al., 2020; Wang et al., 2021), which has been lacking in the study of paediatric liver transplant caregivers. Therefore, this study studied the relationships among caregiver ability, SOC, and caregiver burden of paediatric liver transplant caregivers. This study proposed the following three hypotheses: (1) caregiver ability is negatively correlated with caregiver burden; (2) SOC is negatively correlated with caregiver burden; and (3) SOC partially mediates the relationship between caregiver burden and caregiver ability.

Methods

Study design and setting

This was a cross-sectional study. From April to June 2022, caregivers of paediatric liver transplantation were recruited from a tertiary hospital in China. We used the EQUATOR research reporting checklist STROBE as guideline in this study (File S1).

Participants

The caregivers of children with liver transplantation were the research focus. The following criteria were used for the study. Inclusion criteria for caregivers were (a) the child was treated for the first time with a liver transplant, (b) participants were immediate family caregivers such as parents or grandparents of the child after liver transplantation, (c) participants had normal cognition, and (d) they were informed about this study and voluntarily participated. Exclusion criteria were (a) the child's caregivers had cognitive dysfunction or mental illness, (b) caregivers of children with postoperative survival <3 months, or children with critical illness, poor prognosis, or another systemic complex disease, and (c) caregivers who withdrew from the study midway.

Measurements

Demographics and clinical characteristics

The general demographic information consists of two parts: the general condition of the children with liver transplantation and of their caregivers. Information about the children included gender and aetiology of liver disease. General information about the caregivers included age, gender, marital status, education, residence, employment status, income, and co-caregivers.

Family Caregiver Task Inventory

The Family Caregiver Task Inventory (FCTI) was constructed by Clerk (Clark & Rakowski, 1983) and translated by Lee (Lee & Mork, 2011) to measure the care ability of caregivers. The scale has 25 items, with five dimensions as follow: adapting to care roles, responding and providing assistance, assessing family and community resources, addressing personal emotional needs, and adjusting personal life and care needs. All items are scored on three levels – not difficult (0), difficult (1), and extremely difficult (2) – and the total score has a range of 0–50. A higher score on the scale is understood to indicate the lower the primary caregiver's ability. Reliability and validity of the Chinese versions of FCTI were demonstrated among caregivers, with Cronbach's alpha of 0.873 (Sun et al., 2018). Cronbach's alpha was 0.932 in this study.

SOC Scale-13

The SOC Scale-13 (SOC-13) was developed by Antonovsky (1993) and adapted by Bao et al. (2006) to estimate the caregiver's SOC. The

scale is divided into three dimensions: comprehensibility (five items), manageability (four items), and meaningfulness (four items). Each question is scored on a seven-point Likert-type scale with range 1–7, with five of the items scored in reverse. A higher score indicates a higher SOC (Kenne et al., 2013). The SOC-13 is a valid and reliable questionnaire for use in the Chinese population, with Cronbach's alpha of 0.76 (Zhang et al., 2022). In this study, Cronbach's alpha was 0.886.

Zarit Burden Interview

The Zarit Burden Interview (ZBI) scale was developed by Zarit et al. (1980) and translated by Wang et al. (2006) to measure the care burden of caregivers. The scale has 22 items and consists of two dimensions: individual burden and responsibility burden. Each question is scored on a five-point Likert-type scale with range 0–4, with 0 points meaning never, and 4 points means almost always; the sum score of this scale is 88 points – a higher score indicates a higher burden for caregivers. A total score of 0–20 indicates "No caregiving burden," 21–40 indicates "Mild caregiving burden," 41–60 indicates "Moderate caregiving burden," and 61–88 indicates "Severe caregiving burden" (Zhu et al., 2022). Cronbach's alpha was 0.926 in this study.

Data collection

We used an online survey platform called WenjunXing to collect data. In a group chat with family members of children with paediatric liver transplantation, we provided the questionnaire link and the exclusion standard with unified guidance. Those who met the conditions and voluntarily participated could fill in the questionnaire. To ensure study authenticity, we explained to participants the significance, purpose, and confidentiality of the study. Each participant was asked to fill out the questionnaire independently, and participants could voluntarily withdraw halfway, but those who did not withdraw were required to complete 100% of the questionnaire before submitting it. A total of 461 questionnaires were collected, the 461 questionnaires were valid.

Statistical analysis

Statistical software IBM SPSS version 25.0 was used for all analyses, with all tests two-sided ($\alpha = 0.05$). Continuous variables are presented as mean and standard deviations (SDs), and categorical variables as frequency and percentage. Data normality was assessed using graphs (histogram and Q-Q plot). Caregiver burden scores were normally distributed. The caregiver burden distribution among demographic and clinical characteristics was tested using a *t*-test and one-way ANOVA. Variables with $p < 0.05$ in the univariate analysis were used as control variables in the multivariable hierarchical models. Correlations among caregiver ability, SOC, and caregiver burden were examined using Pearson's correlation coefficients. The potential mediating role of SOC between caregiver ability and caregiver burden was tested using hierarchical multiple regression analysis. Three groups of independent variables were entered in stages into the model. The control variables were entered first (Block 1); then caregiver ability was added (Block 2); and SOC was finally added as a mediator (Block 3). The 5000 bootstrap samples were used via the PROCESS macro for SPSS.25 to further assess the mediating role of SOC. If the BCa 95% confidence interval does not include 0, this indicates a significant mediating effect.

Ethical considerations

Ethics committee approval was obtained for the study. The Declaration of Helsinki (Vanderpool, 1996) was abided by throughout the research, and willingness and voluntariness principles were followed for the family caregivers to participate in the research.

Results

Demographics of participants

Table 1 shows the clinical and demographic characteristics and the univariate model results. The mean age of caregivers was 34.77 ± 6.53 years, and 86.98% were female. Caregivers' residence, education level, employment status, per capita monthly household income, co-caregivers, and the aetiology of liver disease in children were associated with caregiver burden ($p < 0.05$) and so were used as control variables for the hierarchical multiple linear regression model.

Correlations between caregiver ability, caregiver burden, and SOC

Both caregiver ability and SOC were significantly correlated with caregiver burden (Table 2). There was a positive correlation of caregiver ability score with caregiver burden score ($r = 0.523$, $p < 0.01$). However, SOC score was negatively correlated with both caregiver ability score ($r = -0.514$, $p < 0.01$) and caregiver burden score ($r = -0.583$, $p < 0.01$).

Hierarchical multiple regression

Caregiver ability and SOC accounted for 23% and 14% of the variance in caregiver burden, respectively (Table 3). Caregiver ability was significantly and positively associated with caregiver burden ($\beta = 0.75$, $p < 0.01$), and SOC was negatively associated with caregiver burden ($\beta = -0.51$, $p < 0.01$). The data in step 3 show that when SOC was added, the absolute value of the regression coefficient of caregiver ability on caregiver burden decreased from 1.17 to 0.75, indicating that SOC probably had a mediating role in the caregiver ability–caregiver burden relationship.

Path analysis

The mediation analysis is presented in Fig. 1. The total effect of caregiver ability on caregiver burden (path c) was 1.231. The coefficient of path a was −0.894 ($p < 0.01$), of path b was 0.530 ($p < 0.01$), and of path c was 0.757 ($p < 0.01$). Furthermore, the indirect effect of caregiver ability on caregiver burden through SOC was 0.474 (95% confidence interval: 0.301, 0.662), suggesting that the relationship of caregiver ability with caregiver burden (a × b) was partly mediated by SOC. Finally, to determine the mediating pathway effect size, the formula (a × b)/c was used to calculate the proportion of the SOC indirect effect in the total effect of caregiver ability on caregiver burden, with a result of 38.51%.

Scoring indicators on caregiver burden

The distribution of caregiver burden was mild (42.52%), none (26.25%), moderate (24.95%), and severe (6.29%) (Table 4).

Discussion

This study included the largest reported sample of caregiver ability, SOC, and caregiver burden of children who had undergone liver transplantation. We found that the burden of caregivers of children with liver transplantation was not heavy overall, and most experienced a mild burden. We also found that caregiver ability not only directly affected caregiver burden but also indirectly affected caregiver burden through SOC.

In our study, the total mean score for caregiver burden was 32.19 ± 16.71, lower than that of caregivers in Turkey (48.3 ± 24.9, 58.71 ± 11.23, and 67.25 ± 15.59) (Ozdemi & Budak, 2022; Yayan & Duken, 2019; Yayan & Düken, 2020) and Guangxi, China (37.16 ± 12.92) (He et al., 2021). Different cultural backgrounds, measurements, and sample

Table 1
Demographic and clinical characteristics by caregiver burden and results of the univariate analysis ($n = 461$).

Variables	Caregiver burden		t/F	P
	N (%)	Mean (SD)		
Gender of child			−0.822	0.411
Male	222 (48.16)	31.52 (16.77)		
Female	239 (51.84)	32.80 (16.66)		
Aetiology of liver disease			2.659	0.048
Cholestatic liver disease	415 (90.02)	31.60 (16.48)		
Inherited metabolic diseases	13(2.82)	40.08 (23.62)		
Viral hepatitis cirrhosis	4(0.87)	24.75 (10.37)		
Other	29(6.29)	38.14 (15.56)		
Gender of caregiver			−1.312	0.190
Male	60 (13.02)	29.55 (14.97)		
Female	401 (86.98)	32.58 (16.93)		
Age of caregiver			0.528	0.590
≤30	111 (24.08)	32.19 (16.98)		
30–40	268 (58.13)	32.69 (16.79)		
≥40	82 (17.79)	30.52 (16.14)		
Marital status			−1.863	0.063
Married	447 (96.96)	31.93 (16.68)		
Single/Divorced/Widowed	14(3.04)	40.36 (16.05)		
Residence			−2.242	0.025
Urban	266 (57.70)	30.70 (16.28)		
Rural	195 (42.30)	34.22 (17.10)		
Education level			3.444	0.009
Primary school and below	18(3.90)	42.06 (17.10)		
Junior high school	131 (28.42)	34.60 (17.89)		
High school or technical secondary school	98 (21.26)	30.65 (17.71)		
College	97 (21.04)	32.20 (14.55)		
Bachelor degree or above	117 (25.38)	29.24 (15.33)		
Employment status			8.324	0.000
No work	220 (47.72)	35.33 (17.42)		
Part-time job	84 (18.22)	30.94 (16.58)		
Full-time job	157 (34.06)	28.45 (14.90)		
Per capita monthly household income			6.636	0.000
≤2000	91 (19.74)	35.32 (18.21)		
2000–4000	165 (35.79)	34.66 (16.84)		
4000–6000	123 (26.68)	30.71 (16.10)		
≥6000	82 (17.79)	25.95 (13.66)		
Co-caregivers			−3.478	0.001
Yes	298 (64.64)	30.15 (15.92)		
No	163 (35.36)	35.90 (17.50)		

Table 2
Means, SDs and correlations of all variables.

Variables	Mean	SD	Caregiver ability	Caregiver burden
Caregiver ability	6.46	7.17	1	0.523
Caregiver burden	32.19	16.71	0.523**	1
Sense of coherence	55.32	13.91	−0.514**	−0.583**

SD standard deviation.
** $P < 0.01$(two-tailed).

Table 3
Hierarchical multiple linear regression analysis results.

Variables	Caregiver burden		
	Step1(β)	Step2(β)	Step3(β)
Block 1			
Aetiology of liver disease	1.16	0.85	0.52
Residence	0.39	−0.37	−0.25
Education level	0.13	1.06	0.75
Employment status	−1.88	−1.37	−0.97
Per capita monthly household income	−2.33**	−1.52*	−0.72
Co-caregivers	3.29	2.27	1.27
Block 2			
Caregiver ability		1.17**	0.75**
Block 3			
Sense of coherence			−0.51**
R2	0.07	0.30	0.43
△R2	0.07	0.23	0.14

* $P < 0.05$.
** $P < 0.01$(two-tailed).

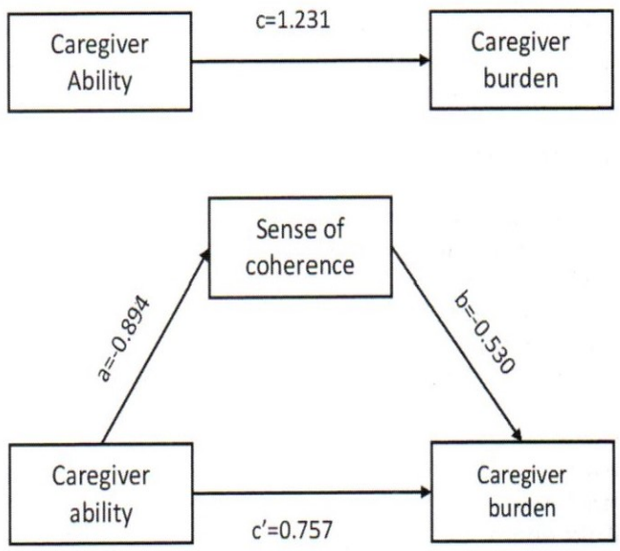

Fig. 1. The hypothesized mediation model relating the effect of caregiver ability on caregiver burden through sense of coherence. Indirect effect of caregiver capacity on caregiver burden through sense of coherence = 0.474 ($p < 0.01$, 95% confidence interval, 0.301 to 0.662).

Table 4
The level of caregiver burden.

Level of burden	N (%)
Absence of burden	121(26.25)
Mild burden	196(42.52)
Moderate burden	115(24.95)
Severe burden	29(6.29)

sizes can explain these variations. We speculate that the most important reason is related to the policy of full surgical funding and the improved management mode of postoperative follow-up (Wu & Gao, 2021). As far as we know, in this hospital, the children not only receive the transplant

surgery for free but also any knowledge related to the disease and care from perioperative to postoperative can be obtained from professionals, such as doctors and nurses, which greatly reduces the financial burden of the caregivers, meets their needs, and ultimately reduces their burden to a large extent.

Our study showed that the higher the caregiver ability score, that is, the lower the caregiver ability, the heavier the caregiver burden, consistent with previous studies (Hu et al., 2022; Wang et al., 2021). In the process of care giving, with a lack of professional care giving knowledge or skills and the conflict of their own role adaptation, the caregiver can have a bad care giving experience, which likely produces a caregiver burden. Therefore, interventions to improve caregiver ability are very important to reduce caregiver burden. Studies have shown that WeChat-assisted health education for parents of infants after enterostomy effectively and continuously provides them with a high quality of medical support, effectively improving their caregiving ability and reducing their caregiving burden (Gao et al., 2021). In addition to the introduction and guidance of disease-related knowledge and skills, the liver transplant team should also strengthen the skills of caregivers to cope with pressure and expand social resources, to better improve caregiver ability and reduce caregiver burden. For example, the construction of Internet-based intervention programs or through qualitative interviews to understand the needs of caregivers, to better improve the ability of caregivers.

From a positive psychology perspective, SOC is positively correlated with caregiver burden (Del-Pino-Casado et al., 2019; Seyedreza et al., 2021), implying that caregivers who find caregiving meaningful, manageable, and understandable, despite their caregiver stress, may be less negatively affected by caregiving. This is consistent with previous research (Potier et al., 2018). Studies have shown that caregivers with a higher SOC perceive less caring burden (Li, 2020; Seyedreza et al., 2021). The reason may be that caregivers with a higher SOC perceive various pressures from children as understandable and have the ability and confidence to control them during the process of caring for children. In addition, they see caring tasks as a challenge rather than a burden, worth the effort and commitment, and have a sense of meaning and accomplishment. Therefore, it is possible not only to screen out high burden caregivers through SOC, but also to reduce the caregiver burden by improving SOC.

More importantly, SOC partially mediated the relationship between caregiver ability and caregiver burden and is consistent with previous study (Li, 2020). One study found that SOC plays a partial mediating role between care giving ability and care giving burden in caregivers of stroke patients with hemiplegia (Li, 2020). The possible explanation is that when caregiver ability improves, on the one hand, the caregiver's cognition of the disease increases and when they encounter the change of the disease, they see these as understandable and predictable, reducing fear and increasing coping ability (Carli et al., 2019). On the other hand, the caregivers' coping resources are enriched and their confidence in caring is increased, which will ultimately reduce their burden. Therefore, methods based on network platforms can be adopted, such as popularizing professional nursing knowledge and skills through public accounts and videos, helping caregivers solve problems and difficulties in a timely manner through wechat groups to improve caregiver ability, and improving SOC through psychological intervention to ultimately reduce the caregiver burden.

Strengths and limitations

First, the sample size of this study is relatively large for studies involving the population of paediatric liver transplant caregivers. Second, this study clarified the direction for the intervention of the burden of paediatric liver transplant caregivers, mainly including the improvement of caregiver ability and SOC. Third, the overall light burden of paediatric liver transplant caregivers in this study is a new conclusion compared with previous studies, which also means that the policy support of the state and the follow-up management mode of the hospital are of great significance to caregivers. This study has several limitations. (i) This is a cross-sectional study, which cannot determine causal relationships among variables. In the future, longitudinal research is needed to confirm the relationship. (ii) The sample of this study is from a single centre, and the results are not representative. We suggest that future multi-centre studies should be conducted. (iii) The scale of FCTI used in this study lacks specificity, and developing a scale for paediatric liver transplant caregivers is desirable.

Implication and future directions

First, the caregiver burden of paediatric liver transplantation can be relatively light. Although the data in this study are not representative on a large scale, it still proves that some measures can be taken to reduce the caregiver burden of this population, such as the funding policy of surgical costs and a comprehensive follow-up management system. Future multi-center studies with larger sample size are needed to verify the results of this study, and explore other influencing factors of caregiver burden, such as transplantation time and liver function. Secondly, the burden of caregivers can be reduced in the future through interventions that enhance caregiver ability and increase SOC.

Conclusion

In our study, the burden of caregivers of children with liver transplantation was generally not heavy. The higher the caregiver ability and SOC, the lighter the caregiver burden. In addition, SOC partially mediated the caregiver ability–caregiver burden relationship. Therefore, to reduce caregiver burden, interventions to improve caregiver ability and SOC should be implemented.

CRediT authorship contribution statement

Dan Zhang: Writing – original draft, Software, Writing – review & editing. **Tiantian Chang:** Data curation, Investigation, Writing – review & editing. **Kaijian Zhao:** Writing – original draft, Software. **He Wei:** Data curation, Investigation. **Shuang Feng:** Data curation, Investigation. **Xiaofei Li:** Conceptualization, Resources, Funding acquisition, Writing – review & editing.

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Declaration of Competing Interest

The authors declare that they have no conflict of interests.

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